Autism Alliance of Canada | Alliance canadienne de l'autisme

Research Collaboration In Focus:

Assessing the Value of a Future National Autism Research Network in Canada

December 2024

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Preface

Autism Alliance of Canada & The National Centre for Autism Collaboration

Autism Alliance of Canada is a registered charity that comprises a diverse membership, including Autistic people, caregivers, clinicians, researchers, policymakers, and autism organizations across Canada. United as a shared leadership movement, we are committed to advancing autism research and policy, ensuring equal rights and opportunities for Autistic people in Canadian society.

With the support of the Joyce Family Foundation through the National Centre for Autism Collaboration (NCAC), our research focuses on systems and policies, addressing the priorities of our members across different regions. Working closely with the government, we integrate lived experiences with national expertise and evidence to effectively shape autism policies.

Emphasizing meaningful inclusion, we actively involve Autistic people in our projects, leading initiatives, providing policy briefings to senior-level officials, leading research and priority-setting, and supporting Autistic scientists and trainees to lead impactful initiatives in both research and policy realms.

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A note from our Scientific Director

I am pleased to introduce our latest report, “Research Collaboration in Focus: Assessing the Value of a Future National Autism Research Network in Canada” that highlights the importance of exploring the value of a coordinated national autism research network.

As outlined in Bill S203, the Federal Framework on Autism Spectrum Disorder Act, establishing a research network is a component of advancing the Federal Government’s National Autism Framework and Strategy. At the Autism Alliance of Canada, we bring together our membership to engage in meaningful conversations to inform the development and implementation of the National Autism Strategy, which supports the National Autism Framework.

Across the country, world-class research on autism and neurodevelopmental conditions is being conducted by national experts and institutions. These efforts are a strong foundation that can be leveraged to develop a national autism network. This network would aim to advance data collection to fill evidence gaps, address priorities identified by autistic people and their families, and aim to understand what programs and services are working for Autistic individuals - unpacking for whom, why, and how. Such knowledge is essential for spreading and scaling successful initiatives, ultimately creating more equitable systems of care and support for autistic people.

A national autism research network could also play a critical role in evaluating the impact of the National Autism Strategy itself, ensuring it delivers measurable outcomes and meaningful change for Autistic people and their families. By connecting Autistic people and their caregivers, researchers, service providers, policymakers, and community organizations, we can build on the expertise already present in the sector to accelerate progress and innovation.

Collecting this initial data is a first small step in bringing people together to shape such a network. We hope this report serves as a starting point for ongoing dialogue and inspires further exploration into the benefits of a unified research ecosystem.

Thank you for your continued support and commitment to this important work.
Sincerely,

Dr. Deepa Singal
Scientific Director, Autism Alliance of Canada

The Report

Context: Autism Research in Canada

Autism research in Canada has made significant advancements over the past few decades, driven by increased awareness, funding, and collaboration across disciplines. Research has shifted significantly from a medical model, which focused on finding biomedical causes and cures for autism, towards an approach that embraces neurodiversity and supports the well-being of Autistic individuals.

This transformation reflects a growing recognition of autism as a lifelong developmental condition and the need to focus on improving quality of life. Research now increasingly emphasizes inclusive policies, support for thriving in society, and understanding autism as a natural variation of human neurobiology, rather than a disorder to be "fixed" (Canadian Academy of Health Sciences, 2022).

In order to leverage the momentum of the research community and address community needs, new initiatives are needed to ensure that research does not take place in silos, to enhance interdisciplinary collaborations and knowledge translation, and to continue to fill gaps in our knowledge.

While existing research has laid a strong foundation, future efforts must continue to be inclusive, impactful, and aligned with the needs of the Autistic community. To maximize the collective potential of the research and broader autism community, we must unite our strengths, leveraging our combined expertise and connections for greater impact.

A National Autism Research Network: In 2023, Bill S-203 outlined the components of a federal framework designed to support Autistic Canadians, their families and their caregivers. One of the measures in the bill is the development of a national research network that will amplify research and further connect the autism research community.

Existing Canadian Research Networks: Research networks focused on autism and other neurodevelopmental conditions exist across Canada. For example, POND (Province of Ontario Neurodevelopmental Disorders) is a network of clinicians, scientists, and researchers working across Ontario that promotes interdisciplinary research to investigate genetics, brain function, and care options for autism and other conditions. TACC (Transforming Autism Care Consortium) is a Quebec-based research consortium working to advance care and understanding of autism through interdisciplinary collaboration between researchers and clinicians. CHILD-BRIGHT is a pan-Canadian network focused on enhancing well-being and improving outcomes for children with brain-based developmental disabilities, including autism, bringing together researchers, families, clinicians, and policymakers. Finally, KBHN (Kids Brain Health Network) is a national network that focuses on translating research into practice by supporting the development of innovative interventions, tools, and policy changes that directly impact children and families.

The work of existing networks has been instrumental in advancing autism research and supporting Autistic people and their families across Canada. However, with the passage of Bill S-203 and the announcement of a National Autism Strategy, the creation of a dedicated national autism research network is being considered to build on and unify current efforts specifically for autism.

Why we did this survey

Autism Alliance of Canada is committed to ensuring that the implementation of the National Autism Strategy is inclusive, evidence-based, and involves Autistic people and their caregivers. The Alliance, with its extensive network of Autistic people and their families, clinicians, researchers, policymakers, service providers and organizations from across Canada, is uniquely positioned to identify the needs for a national autism research network that will advance high-quality research that reflects community priorities. By convening its members, the Alliance calls on a wide range of expertise and lived experience to guide the development of a national research network.

Exploratory work is essential to ensure that a new national autism research network in Canada offers real value and complements existing networks, without duplicating their efforts. This process allows us to identify gaps and opportunities for collaboration that can lead to new, impactful research and policy initiatives. The survey was conducted to ensure that the voices of community members—Autistic individuals, their families, researchers, and service providers—are heard and that their priorities are documented as the network is developed.

This work has aimed to gather input from individuals to help guide and shape the development of such a network, ensuring it supports coordinated, lifelong services, equitable delivery, and the integration of research into policy for Autistic Canadians across the country.

This report presents the findings of an exploratory survey that Autism Alliance of Canada conducted to gain insight into the expectations and priorities of both the autism community and the research community for a national autism research network. These insights provide a foundation that can guide the effective development and implementation of the network in alignment with Canada's Autism Strategy.

What we did

The research team at Autism Alliance of Canada drafted a survey with two separate streams, assigned based on the respondent's main identity:

1. **Research survey:** for academics, researchers and research students/trainees
2. **Community survey:** for the community, including people with lived experience of autism or disability in general, family members, services providers, health professionals, and employees at community organizations.

The questions in both surveys were similar but worded differently to ensure accessibility and adaptation to both groups. Different types of questions required participants to select multiple-choice responses, indicate their top priorities, or write a short text answer. Respondents were asked to share their views on how a research network could add value to their lives, what they would like to contribute to it, and how they would like to engage. The survey was disseminated through Autism Alliance of Canada's newsletter and social media, and direct emails to research teams working on autism across the country.

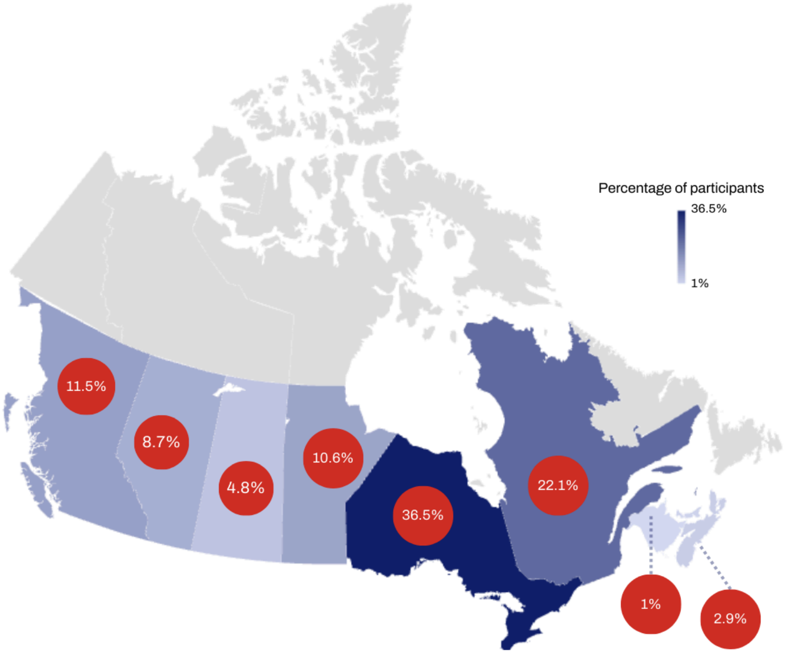
Responses were collected in French and English during March and April 2024.

Who participated

Geography

One hundred and twelve (N = 112) people representing most Canadian provinces responded to the survey. The Territories and the Atlantic provinces were underrepresented.

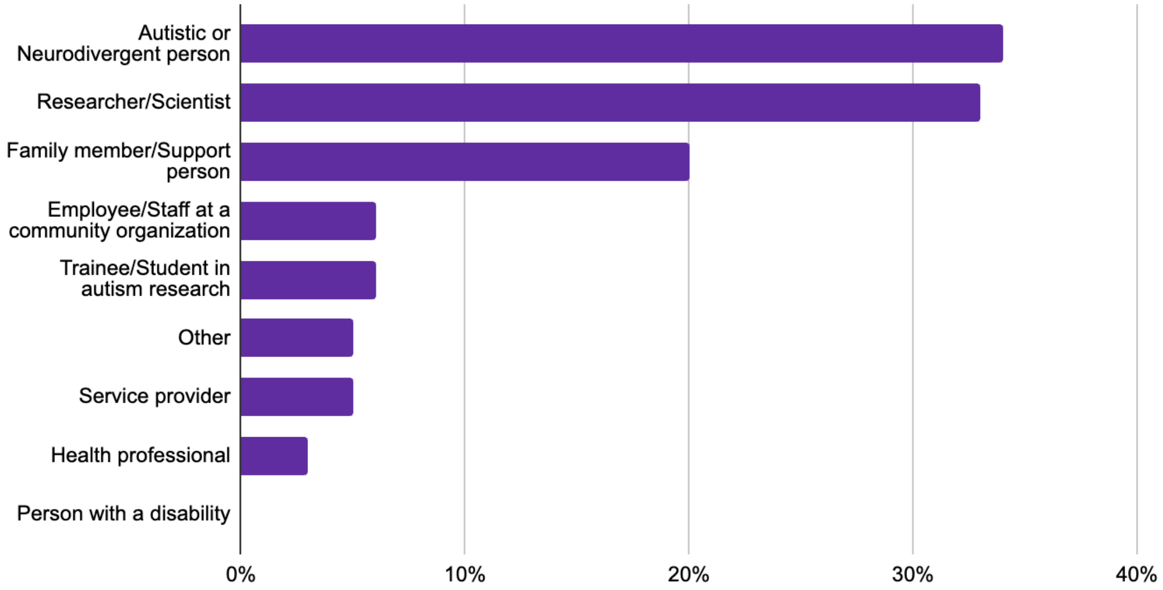
Figure 1: Percentage of participants from each Canadian province and territory who responded to the survey. The grey zones indicate 0 participants.



Main identity

Thirty-nine participants (35.2%) filled out the Research survey and 73 (64.8%) the Community survey. When asked to choose one main identity, 30.4% of respondents identified as Autistic or Neurodivergent. Researcher/Scientist was the second most represented identity (29.5%), and Family member/Support person was the third one (17.9%). Although we tried to get a wide diversity of respondents, our results are not representative of the whole population.

Figure 2: Percentage of participants by the main identity they selected



Key findings

This section describes the key findings from both surveys. It contains quotes from the survey participants. The quotes are set apart from the main text with quotation marks. We decided not to edit the original comments, including spelling or grammar mistakes, to keep the participant's voice authentic. We added details like main identity and province for context but removed personal information to protect privacy.

1. Bringing Value: What do members hope to gain from joining a national research network?

Participants were asked to pick the 3 things that would add the most value to the network for them within a list of options. They could also type in their answer.

More than half of the community survey respondents said they wanted to participate in **setting research priorities that reflect community needs** (61.6%) and to **influence how policies are made** (58.9%). They seek a research network that not only acknowledges their needs but also actively incorporates their input into the research process and policy-making.

> **"Lived experience and autistic researchers should be prioritized first and foremost."** Family member/Support person, Manitoba
>
> **"This network would be different as it would have the participation of autistic members that can share from their lived experiences. As well as clinicians and parent partners who live, work, and work in the field of studying autism."** Autistic or Neurodivergent person, Saskatchewan
>
> **"Unifying the disability community by advocating & pushing for policies and systems that will end up benefiting all those with disabilities."** Autistic or Neurodivergent person, Alberta

Community members also expressed that they wanted to work with research teams on projects (42.5%) and be informed about the latest research (37.0%), emphasizing the importance of fostering collaboration between researchers and the community, specifically by involving people with lived experience as active partners in research. Knowledge dissemination was also mentioned as a key point to raise awareness and foster collaboration.

> **"Autistic people should be involved as decision makers in this network"**
> Autistic person, PEI

The primary priority of Researchers was to have the opportunity to collaborate with other network members on interdisciplinary research projects and grants (56.4%). There was a wide variety of domains of expertise among the respondents who were eager to contribute their expertise in various methodologies and research skills, including grant writing, knowledge translation activities, and participatory research. This interest reflects a commitment to working together and fostering a collaborative research environment. Participants highlighted the need for transparency throughout the research process and the operationalization of the network to achieve buy-in from both the research and autism communities. Most researchers (53.8%) were hoping to engage with persons with lived experience and gain access to diverse perspectives to ensure that their studies genuinely reflect and address the diverse needs of the community.

> **“I hope this truly ends up being inclusive and used to amplify the voices and needs of autistic people who need it the most, and supports research processes for new researchers” -** Researcher, Ontario

Lastly, researchers highlighted their need to access shared resources, such as funding opportunities (41.0%), professional development or training (43.6%), and research data (23.0%). There was strong enthusiasm for a research network that promotes collaboration and mentorship, reducing the silos that currently exist.

Figure 3: Main priorities identified in the Community and Research Surveys for what would bring value to a national autism research network

Community Survey		**Research Survey**
What would you hope to get from joining a research network?		How do you envision a national autism research network adding value to your existing work and professional development?
Participate in setting research priorities that reflect community needs	**1**	The opportunity to collaborate on interdisciplinary research projects and grants
Influence how policies are made	**2**	Engagement with persons with lived experience and access to diverse perspectives
Work together with research teams on projects	**3**	Access to funding opportunities
Learn about the latest research in the field	**4**	Professional development and training opportunities for researchers and/or trainees

2. Key Events and Activities of the Network

We asked participants to select three priority events or activities that they would like to have in a network. Both surveys revealed that participants wanted to participate in priority-setting exercises to focus research questions on community needs. The community was interested in online presentations, skill training, and policy advocacy events. The top priority for Researchers was to have an annual conference where autism researchers from across Canada could meet and share their work. The responses highlighted the need for both pan-Canadian events to learn, collaborate and share knowledge and resources, and community engagement to better align research priorities.

Figure 4: Main priorities identified in the Community and Research Surveys for the type of events and activities to have in a national autism research network

Community Survey What types of events or activities would you like to have in the network?		**Research Survey** What types of events or collaborative initiatives would you like to see organized within the network?
Deciding on important research questions that match what the community needs and cares about	**1**	In-person annual conference on autism research in Canada
Online presentations	**2**	Priority setting exercises to identify priority research questions consistent with the community's needs
Training sessions and workshops to learn new skills	**3**	Working on a pan-Canadian grant with other researchers
Events for speaking up about policies	**4**	Training and mentorship programs

3. Accessibility of the Network

We asked participants in the Community survey about the support that would make it easier for them to participate in a research network. Participants noted that due to geographical distances and financial constraints, attending meetings in person poses a significant challenge. These limitations often hinder their ability to fully engage in collaborative activities and contribute as effectively as they would like. To address this, participants suggested implementing both in-person and virtual meeting options with flexible timing. This approach would accommodate different schedules and locations, making it easier for all members to participate and collaborate effectively. In both surveys, emails were the preferred mode of communication for nearly all participants. Virtual meetings were preferred over in-person meetings.

Figure 5: Main modes of communication identified in the Community and Research Surveys for a national autism research network

Community Survey		**Research Survey**
How would you like us to talk to you about the network?		What platforms or modes of communication would be most convenient and effective for your engagement with the network?
Email (97.1%)	**1**	Email (89.5%)
Virtual Meetings (72.9%)	**2**	Virtual Meetings (89.5%)
In-Person Meetings (51.4%)	**3**	In-Person Meetings (55.3%)
Online forums or discussion boards (47.1%)	**4**	Online forums or discussion boards (34.2%)

> **"As I live in Northeastern Ontario, distance to events makes a difference. Online options or considerations for people who live outside of major centres (such as Toronto or Ottawa, etc) would allow for equal and inclusive access and representation."** Autistic or Neurodivergent person, Ontario

Other facilitators that would encourage the Community to participate were community-building activities (75.3%), access to free learning opportunities about the research process (65.8%) and helpful resources (68.5%), and monetary compensation (60.3%). Participants underscored the importance of treating them as research partners and actively involving them in the process, allowing for different forms of communication to be equally valued. This approach requires an engagement strategy that gives them the necessary tools to be meaningfully involved and values their contribution. Moreover, promoting bilingualism in English and French was deemed essential for facilitating effective pan-Canadian engagement and collaboration between different groups.

> **“Having professionals/partners that want to work with us not for us”** Parent and professional, British Columbia

> **"Financial support - us autistic folks are struggling financially and it takes what we've got energy-wise to survive any sort of employment so we can offer our participation in this type of thing voluntarily - pay us so we can put our energies into this and still eat, encouraging all methods of communication - not just spoken word (presentations, workshops, synchronous training requiring group participation verbally etc.) Value written contributions (...) as EQUAL to those who speak. Have someone who can read out comments from those using text options so they are included."** Autistic health professional, person with a disability, service provider and student in autism research, Nova Scotia

4. Research Priorities

Participants were asked to share the key research areas that should be prioritized in the research network to have a greater impact on transforming systems for Autistic people and their loved ones. They could type their answer freely, and we compiled the most recurrent themes. We found that the researchers and the community agreed on several of the top priorities, but there were also priorities that the community deeply cared about that were not mentioned by researchers, showing the need for collaboration to share diverse perspectives and align priorities.

The most frequent answers along with the rounded-up percentage of participants in each survey who mentioned each topic are presented below:

Research priorities mentioned in both surveys

- **Support systems (28% Community, 41% Researcher):** Support systems refer to resources aimed at supporting the well-being of individuals.
- **Social Science (15% Community, 36% Researcher):** Social science is defined as the study of human society and social relationships among people.
- **Mental Health (16% Community, 10% Researcher):** Mental health refers to the emotional, social and psychological well-being of people.
- **Education (16% Community, 5% Researcher):** Education is important to equip individuals with the knowledge to thrive in society. There is a need to ensure it is inclusive and accessible for all.
- **Participatory Research (11% Community, 15% Researcher):** Participatory Research is defined as research that involves the communities or people being studied.

“There remains a gap in current knowledge and understanding of how autism presents outside of stereotypes. Research that allows us to understand what the current level of knowledge is among medical professionals, educators, and the general public and what gaps in understanding/knowledge and training exist would allow for a baseline and foundation from which to build on.” Autistic or Neurodivergent person, Ontario

“More focus on autistic led, diverse, community engaged approaches, and collaboration with family, kin, and educators and practitioners who wish to change systems. “ Researcher, Ontario

Research priorities mentioned in the Community Survey

- **Intersectionality (26%):** Intersectionality defines the overlapping social identities that influence how Autistic people navigate the world, impacting their access to resources, support, and acceptance. Several participants mentioned the need to study autism in girls and women.
- **Aging/Adulthood (21%):** Once Autistic individuals enter adulthood they often lose access to various government supports. Because of this, there is a need to study autism across the lifespan to ensure the community is supported.
- **Employment (21%):** According to the Government of Canada, 80% of Autistic people or people with intellectual disabilities are unemployed. There is a need to understand the policies that promote equal opportunities, economic independence, and thereby enhance the quality of life of Autistic people.
- **Autism Diagnosis (14%):** Obtaining an autism diagnosis is important to enable access to supports and services tailored to Autistic people's needs. This requires a system that is accessible for people from all backgrounds and ages.
- **Co-occurring Conditions (5%):** Co-occurring conditions refer to the medical, psychological, or developmental conditions that are often present alongside autism, such as ADHD, epilepsy, digestive issues, and sleep disorders. These conditions can add additional challenges that can impact the quality of life of Autistic people.

"More Autistic-led research with focus on how environments (school, Healthcare, occupational, community) shape the Autistic experience of the world and how shaping a more inclusive society/environment, rather than expecting the Autistic person to "fit in" improves Autistic people's well-being and "success" rates." Autistic person, Ontario

“Focusing research on areas that align well-researched autism/disability issues with provincial and national political interests. There may be many needs, but how do we move the bar. At what point do we empower people individually vs waiting for public policy change? Can we do both, and how? How can we empower people to speak in ways that encourage public engagement & investment rather than only saying the needs are great and endless?” Employee at a community organization, Ontario

“The current functioning of public & private healthcare system that autistic people have to utilize for diagnostic services & support/referral needs to be reviewed at a national level for all age groups. In my local city, I faced significant barriers to receiving my diagnosis & supports, and I fear that many undiagnosed & diagnosed people are falling through the cracks of the system.” Autistic person, Alberta

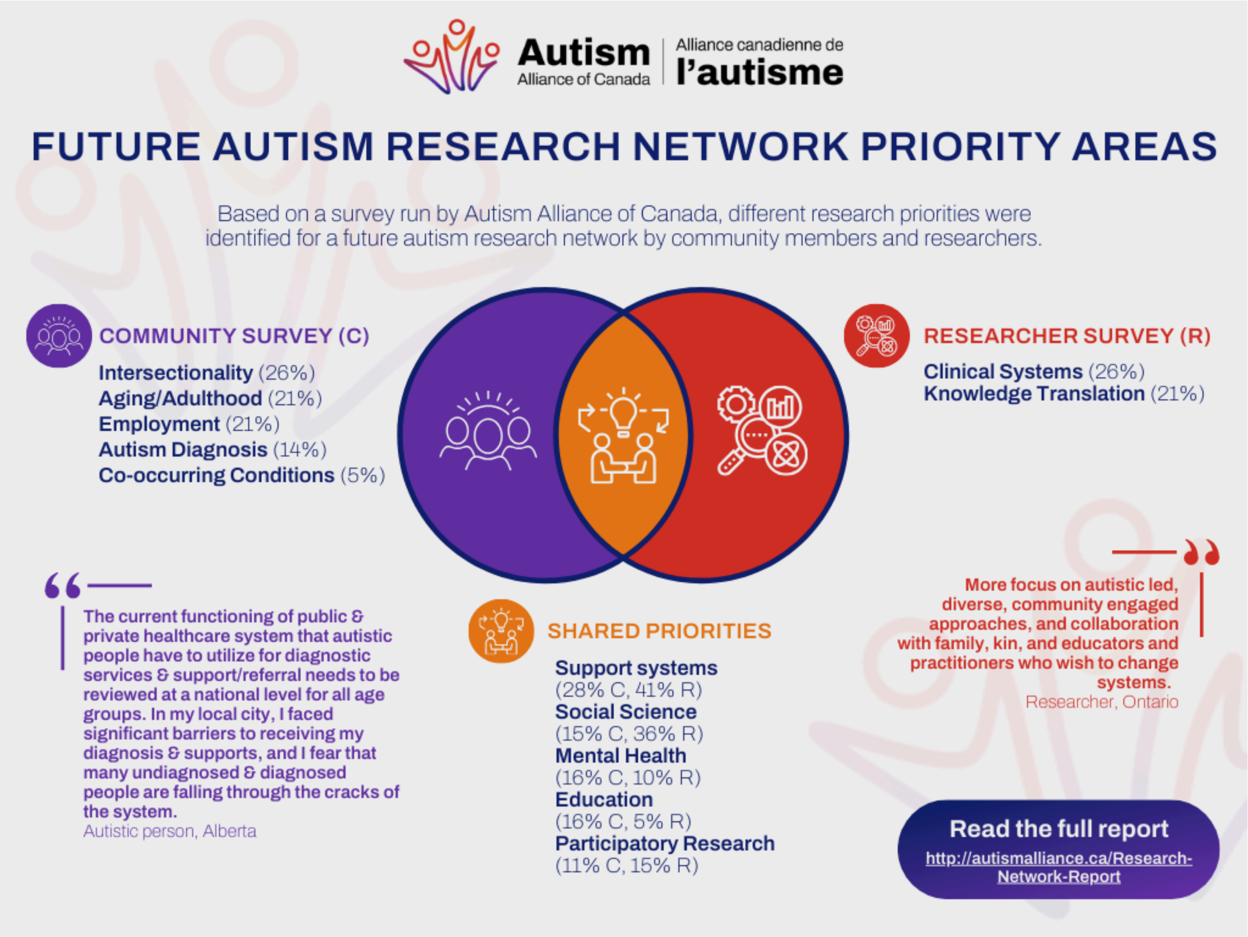
Research priorities mentioned in the Research survey

- **Clinical Systems (26%):** There is a need to improve the clinical systems and infrastructure in place to best support Autistic people.
- **Knowledge Translation (21%):** Knowledge translation refers to the process of transforming knowledge into practical applications, for example through policy. The goal of knowledge translation is to ensure the knowledge generated through research has a tangible impact.

“I believe that basic and social sciences are both critical in improving the quality of life of autistic individuals and their families. This being said, conducting research on knowledge brokering and translation within the autism community in Canada, along with disability and autism policy, should be an essential first step for this network, given the timeline outlined in Bill S203.” Trainee/Student in autism research, Quebec

“Clinical and social sciences, especially with a focus on autistic people with intellectual disability or those who are nonverbal. Research predominantly includes autistic people who are verbal and those who have at least average intellectual functioning.” Researcher, Ontario

Figure 6: Visual summary of the priority research areas identified in the Community and Research Surveys for a national autism research network



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FUTURE AUTISM RESEARCH NETWORK PRIORITY AREAS

Based on a survey run by Autism Alliance of Canada, different research priorities were identified for a future autism research network by community members and researchers.

COMMUNITY SURVEY (C)

Intersectionality (26%)
Aging/Adulthood (21%)
Employment (21%)
Autism Diagnosis (14%)
Co-occurring Conditions (5%)

RESEARCHER SURVEY (R)

Clinical Systems (26%)
Knowledge Translation (21%)

> **The current functioning of public & private healthcare system that autistic people have to utilize for diagnostic services & support/referral needs to be reviewed at a national level for all age groups. In my local city, I faced significant barriers to receiving my diagnosis & supports, and I fear that many undiagnosed & diagnosed people are falling through the cracks of the system.**
> Autistic person, Alberta

SHARED PRIORITIES

Support systems
(28% C, 41% R)
Social Science
(15% C, 36% R)
Mental Health
(16% C, 10% R)
Education
(16% C, 5% R)
Participatory Research
(11% C, 15% R)

> **More focus on autistic led, diverse, community engaged approaches, and collaboration with family, kin, and educators and practitioners who wish to change systems.**
> Researcher, Ontario

Read the full report
http://autismalliance.ca/Research-Network-Report

Where do we go from here?

This report highlights the shared vision between the autism community and the research community for a national autism research network. Both groups strongly advocate for inclusive, participatory research that centres lived experience, provides training for its members, and promotes interdisciplinary collaboration.

Moving forward, the creation of a national autism research network must reflect these shared priorities. One of the federal actions described in Canada's first Autism Strategy is the establishment of such a network, emphasizing inclusive and participatory research approaches. By amplifying Autistic voices, facilitating cross-sector collaboration, and ensuring accessibility, this network can become a powerful tool for transforming systems, advancing impactful research, and informing policy. This report lays the groundwork to build a cohesive, inclusive network that will shape the future of autism research and policy in Canada.

There is critical work ahead to bring this vision to fruition. Key discussions must focus on defining the scope and vision of the network, assessing its value-add to the existing research landscape, and identifying how it can best leverage and complete current efforts. Thoughtful consideration is also needed to determine its alignment with exciting research priorities and frameworks, ensuring it enhances rather than duplicates efforts.

Additionally, practical questions about the logistics of setting up the network must be addressed. These include identifying leadership, operational structures, and funding mechanisms, as well as clarifying roles and responsibilities among researchers, policymakers, and community organizations. Input from thought leaders and diverse stakeholders will be essential to ensuring the network reflects the needs and priorities of the autism community while fostering innovation and inclusivity.

The next steps involve convening stakeholders and national leaders to co-develop a roadmap for this network. These discussions should include determining how to prioritize research gaps and engage Autistic people and their families meaningfully. Establishing governance structures and ensuring sustainable funding will also be critical to the nework's success.

Support from the general government in terms of funding and resources will be essential to realizing this vision. Federal investment will ensure that the network is robust, sustainable, and equipped to drive forward the goals of Canada's Autism Strategy.

The opportunity to create a national autism research network represents a pivotal step toward improving the lives of Autistic people by advancing research that directly addresses their needs. By building on the strong foundation of work already underway and centering the voices of those with lived experience, this network can drive meaningful progress—focusing on research that informs policies and practices to create tangible, positive change in the everyday lives of Autistic individuals and their families.

Acknowledgements

Project team

Dr. Alexia Ostrolenk, HSIF Postdoctoral Fellow
Marina Schor, Research Coordinator
Sayyam Shah, Summer Research Intern
Dr. Deepa Singal, Scientific Director

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Learn more about the Alliance

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